



THE
Journal

OF THE ARKANSAS MEDICAL SOCIETY

Vol. 105 No. 12

JUNE 2009

Hospice
and the "End-of-Life"
Discussion

It's About Living, Not Fighting Death

THE Journal

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Hospice and the “End-of-Life” Discussion

By **Cathy L. Pugh**

It's About Living, Not Fighting Death

Troy Gray was all about living. Did that have to change, because he was dying?

During their 58 years together, his wife, Geneva, had known him as a lover and a fighter. He had been a professional

boxer, who, outside the ring, was her constant companion and a stranger to none. In mid-life, he was a loving father and an avid gardener. Even late in life, as he battled Alzheimer's disease and heart problems, it was all about living.

For that reason, Geneva wanted him to enjoy his last days in dignity and comfort at the Hospice Home Care Inpatient Facility on Bowman Road. There, she could focus on him while the staff handled his care and assisted with personal and family matters.

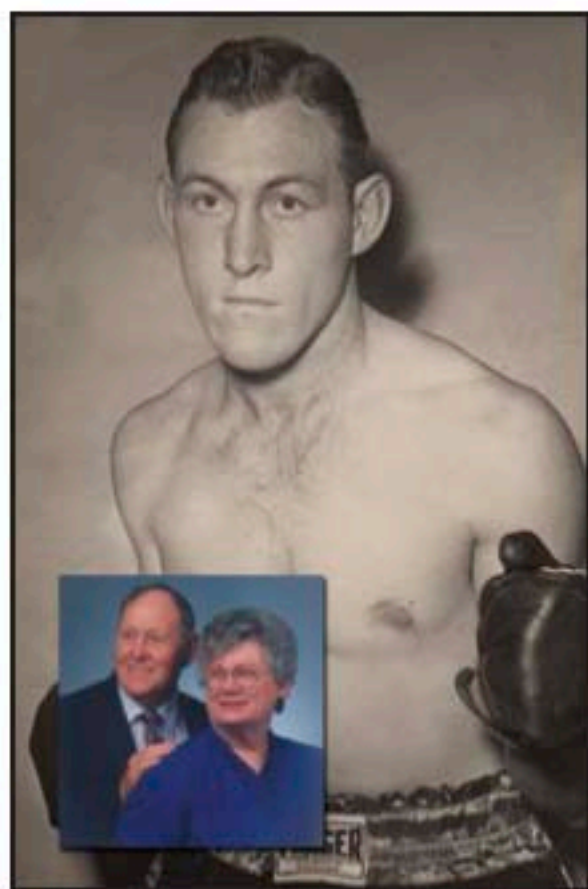
Troy Gray died in the summer of 2005 – pain-free and surrounded by his entire family. “Hospice House was most gracious,” recalled Geneva. “They didn’t take the pain [of losing him] away, but they did make it easier.”

Specialized care for the dying has been available in the United States since the early 1970s, growing from modest beginnings to a widespread — and Medicare-covered — practice today. The National Hospice and Palliative Care Organization (www.nhpc.org) describes hospice as

a team-based approach to care for patients close to death; involving medical care, pain management, and emotional and spiritual support for them and their caregivers. Today, the United States has more than 1,400 hospital-based palliative care teams and more than 4,700 hospice programs, reports the *Journal of the American Medical Association*.

Though access has grown exponentially in recent years, hospice is still relatively underutilized. Nationally, around 30% of eligible dying patients receive hospice care. Last year in Arkansas (data is from Sept. 2007 to Sept. 2008), 33% of eligible dying patients were under hospice care.

Those numbers mask a troubling reality, however. According to Neal Wyatt, DO, corporate medical director of Arkansas Hospice, about 50% of hospice patients nationally die within three weeks of admission. “Though we admit many, we admit them (in our eyes) much later than when they actually first need us; we are not able to have as much impact for them and their families as we would like,” he said. “Also, there is a wide variation from county to county. Almost 50% of deaths in Washington County occurred under hospice care, while in Yell County only



Troy Gray, professional boxing photo. Inset: Troy Gray with his wife, Geneva.



Neal Wyatt, D.O., Corporate Medical Director of Arkansas Hospice. Photo: Candice S. Milwood

16% occurred. The same holds true on a national level. Rural areas have fewer people receiving hospice care than in more populated areas."

Why aren't more people choosing to die like Troy Gray? While access is

an issue, another more personal reason is just as important: Nobody – not patients, not families, not physicians – likes to talk about death.

Oncology nurse Mischelle Wilson has seen this dread – even fear – of

discussion firsthand from physicians and family members. "I can say that many do not understand – or [they] feel threatened by – all that hospices have to offer our families," said Wilson, whose mother recently enrolled a loved one in hospice. "The moment we called Odyssey [Healthcare of Little Rock], they were reassuring, calm, informative and just plain nice. They walked those two through the admission process, and I am sure will share more information as the need arises. My mother is much more at ease. She is able to sleep now because she feels like she can call on someone else to make decisions as to how sick he is or what he needs."

Having the End-of-Life Discussion

Experts say – and research suggests – that communication is the key to increasing hospice beneficiaries in Arkansas and nationwide. A study discussed in the *Journal of the American Medical Association* revealed a correlation between end-of-life discussions between patients and





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physicians and less aggressive care and better quality of life before patient death. The study (from 2002 to 2008) followed 332 advanced cancer patients from enrollment to death (about four months) and followed patients' informal caregivers' psychiatric health and quality of life up to about six months after patients' death. Its authors concluded, "By acknowledging that death is near, patients, caregivers and physicians can focus on clarifying patients' priorities and improving pain and symptom management."

Moreover, they wrote that, "More aggressive care was associated with worse patient quality of life and higher risk of major depressive disorder in bereaved caregivers, whereas longer hospice stays were associated with better patient quality of life." In addition, higher patient quality of life was associated with higher caregiver quality of life at follow up.

As a medical director of hospice patient care in Arkansas and as a family

medicine and hospice-and-palliative-medicine-certified physician, Dr. Wyatt has had EOL discussions with patients in home hospice care, in nursing homes, and in hospitals. Such talks

"So many would say that all they wanted was for their loved one's last days to be comfortable, but they didn't understand [until then] that there was a way outside of the aggressive hospital model of care to make that happen."

— Neal Wyatt, DO

are rarely as difficult as physicians fear them to be. "Sometimes we feel that this discussion will cause the person to lose hope," he said. "So many

times, I've seen the opposite occur. Ultimately, I think doctors have just as much of a problem with mortality – their own and others – as the rest of the population."

According to Janice Rogers, a clinical practice specialist in palliative care for Baptist Health, effective EOL discussions eliminate misconceptions and increase acceptance of palliative care and hospice. On the other hand, ineffective EOL discussions can be detrimental to patients and families. "I would love to see health care professionals eliminate the phrase 'there is nothing more we can do for you,' which leaves a sense of despair and hopelessness," she said. "There is always more that can be done – even when a cure is no longer within reach. As the focus of care shifts from curative measures, we can do everything possible to manage distressing symptoms such as pain and dyspnea, preserve dignity in living, and support the patient and caregiver."

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Dr. Wyatt, too, feels that physicians' understanding of hospice plays a role in patient outcomes. He recalls feeling inner turmoil when, as a hospitalist, he struggled to deal with patients he knew were dying. "I continually faced patients with terminal conditions," he said. "They were making trips back and forth to the hospital and had been for some time. Initially, I felt conflicted and nervous in these situations."

Dr. Wyatt decided to embrace the truth with his patients. The response overwhelmed him. "Patient after patient and family after family would break down with tears of relief when I explained to them that they had an alternate choice besides coming back and forth to the hospital all the time," he said. "So many would say that all they wanted was for their loved one's last days to be comfortable, but they didn't understand [until then] that there was a way outside of the aggressive hospital model of care to make that happen. Very quickly this turned from something I was resigned to do to a burning passion to help people understand all of their options for their care."

Leading Your Patients to Hospice

It's essential to lay the groundwork before referring patients to hospice, experts say. The sooner Dr. Wyatt can engage in discussions with physician and patient, the better the outcome – for many reasons. "One of the hardest things in my current job is walking in 'cold turkey' to a family I have never met to try and discuss these issues," he said. "There is no way I can build the trust that they have for their long-term physician or physicians in such a short time."

Dr. Wyatt said that, during the dying process, palliative medicine physicians can assist physicians, patients and their families in areas other than hospice. "We are specialists in symptom management and often can help with refractory symptoms long before someone is ready for hospice care," he

said. "At the same time, by bringing us on board early to help with symptoms, we are able to build the trust and rapport with patients and families. This makes us a valuable asset for busy physicians when it comes time to have discussions about end-of-life options."

Ultimately, Dr. Wyatt said physicians may worry unnecessarily about turning patients "over" to hospice. "You don't have to feel you're abandoning patients when you refer them to hospice," he said. "You have the opportunity to continue as the patient's physician in hospice services, and the hospice physician will serve in a consultative role to you."

"Receiving hospice [also] doesn't mean you stop treating 'everything.' The way the Medicare hospice benefit is structured, you are only in hospice for your terminal or life-limiting diagnosis; diseases not related to your hospice diagnosis can continue to be treated just as before," he said. "A classic example is someone in hospice for heart failure. The person may fall and break their hip. They can go to the hospital and get their radiology tests, orthopedic consultation, surgery and physical therapy without ever having to come off hospice."

Dr. Wyatt — and other local experts — want to see more people die in comfort rather than in pain. He encourages readers to contact him for further discussion (nwyatt@arkansashospice.org). He also recommended educational materials, ethical position statements, and other valuable resources available through organizations like the National Hospice and Palliative Care Organization (www.NHPCO.org) and the American Academy of Hospice and Palliative Medicine (www.AAHPM.org).

"You see, it's not about losing hope or giving up," he said. "It's about allowing patients to know the truth about their terminal diagnosis and ensuring that patients and families know there are options other than aggressive treatments and crisis mode." **AMS**



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